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Telemedicine for outpatient palliative care during COVID-19 pandemics: a longitudinal study

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ABSTRACT

Objectives During the COVID-19 pandemic, telemedicine (TM) emerged as an important mean to reduce risks of transmission, yet delivering the necessary care to patients. Our aim was to evaluate feasibility, characteristics and satisfaction for a TM service based on phone/video consultations for patients with cancer attending an outpatient palliative care clinic during COVID-19 pandemics.

Methods A longitudinal observational study was conducted from April to December 2020. Consecutive patients were screened for video consultations feasibility. Either patients or their caregivers received video/phone consultations registering reason and intervention performed. Those contacted at least twice were eligible for experience of care assessment.

Results Video consultations were feasible in 282 of 572 screened patients (49%, 95% CI 45% to 52%); 112 patients among the 572 had at least two phone/video consultations and 12 of them had one or more video consultations. Consultations were carried out with patients (56%), caregivers (30%) or both (14%). 63% of the consultations were requested by the patients/caregivers. Reasons for consultation included uncontrolled (66%) or new symptom onset (20%), therapy clarifications (37%) and updates on diagnostic tests (28%). Most interventions were therapy modifications (70%) and appointments' rescheduling (51%). 49 patients and 19 caregivers were interviewed, reporting good care experience (average of 1–5 satisfaction score of 3.9 and 4.2, respectively). The majority (83% and 84%) declared they would use TM after the pandemics.

Conclusions Although feasibility is still limited for some patients, TM can be a satisfactory alternative to in-person visits for palliative care patients in need of limiting access to the hospital.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Telemedicine in palliative care was used with heterogeneous evidences about its impact.

WHAT THIS STUDY ADDS

⇒ Telemedicine feasibility is limited but reaches high overall patient/caregiver satisfaction.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE AND/OR POLICY

⇒ Telemedicine is a promising tool to facilitate patient–clinician interaction, however, clinical impact and cost-effectiveness should be better documented.

BACKGROUND

On 11 March 2020, due to the constantly increasing number of cases worldwide, the WHO declared the COVID-19 outbreak as a pandemic.¹ After the first patient being diagnosed with COVID-19 on 20 February 2020, numbers of affected patients in Italy increased sharply thereafter, particularly in Lombardy.²

Considering the need to reduce the risks of transmission of COVID-19 due to close contact among patients and with clinicians, telemedicine (TM), has emerged as a mean to deliver care.³

TM has been defined in multiple ways.⁴ In this paper, we embrace the following definition that is also adopted by the Italian Ministry of Health⁵: ‘... the use of technologies and telecommunication systems to administer healthcare to patients who are geographically separated from providers’.

TM has been used before in the palliative care (PC) setting and has gained approval as an acceptable and promising methodology in supporting patients at

home.^{6–11} However, numerous issues have been raised, mainly related to the best setup and individualisation of such PC interventions. In consideration of the worldwide emergency situation, attempts have been made to provide TM service to these patients, leading to the publication of practical tips that cover TM setup and both patient and clinician considerations.¹² Several recent papers have provided a description of the transition from in-person to TM visits, indicating the feasibility of providing continuity of care for palliative patients by also reducing their chances of contacting the virus.^{13–16} However, more information is needed regarding the impact of the implementation of this strategy on patient management and experience of care.

Although the definition of TM reported above⁵ is quite broad and includes any information and communications technology-based remote contact with the patient, video consultations constitute the most clinically relevant approach, allowing a better evaluation of the patients' general physical condition and performance status. Nevertheless, patients with advanced cancer are frequently old people who may lack the needed IT literacy and/or adequate technology devices to easily establish a video consultation.¹⁷ Systematic assessment of technological devices availability and of IT literacy in this patient population is still limited.^{18–20}

To address the COVID-19 epidemics situation, a TM service based on phone or video consultations was organised for patients with cancer attending an outpatient PC clinic within a comprehensive cancer centre in Milano, which has been one of the most affected areas in Lombardy of COVID-19.²¹

The main aims of this study were to investigate patients' and caregivers' experience of care with TM consultations for cancer patients attending an outpatient PC clinic during the first and second wave of the COVID-19 pandemics. Secondary aims were to describe the implementation of the TM service and estimate the feasibility of the video consultations in such population.

METHODS

Study design and population

This is a prospective observational longitudinal study consisting of two phases: feasibility phase and implementation description/user experience phase. All consecutive patients, either first visits or follow-ups, aged 18 or more, seen at the outpatient PC clinic of our institute and scheduled to have a visit in the period from May to December 2020, were screened for video consultation feasibility. Independently from this, the TM service (consisting in either a phone or video consultation) was offered to all patients, when needed. Those with at least two TM consultations were included in the implementation description and were eligible for user experience assessment.

Screening for video consultation feasibility

All consecutive patients seen in the outpatient PC Clinic during the enrollment period were screened for video consultation feasibility. The following issues were assessed: availability of devices such as a smartphone, tablet, computer with webcam; availability of email and of a stable internet connection; need of help/support for participating in videocalls and, if needed, the availability of such help. Patients were considered to have technical availability when they had at least one of the devices required for participating in the video consultations, an unlimited internet connection and an email address. Video consultation was deemed feasible if the patient had technology availability, did not need help (or had help if needed) and reported to accept it. Age (18–60, 60–75 and 75 or higher) and sex were also registered. All data were anonymously collected asking patient oral informed consent.

The PC TM service during COVID-19 pandemic

The TM service consisted in a phone or videocall (for those who had internet access and the appropriate hardware/help) mimicking the in-person clinical encounter with the PC specialist. The call was carried out to reschedule the appointment in concomitance with oncology follow-up and treatment visits (in order to reduce patient access to the hospital) or to respond to patient/caregiver request.

The interventions/evaluations performed during the call included:

- ▶ Evaluation of patient physical and psychological symptoms, functional status and well-being including signs of potential COVID-19 viral infection.
- ▶ Evaluation of the potential onset or worsening of drug side effects.
- ▶ Visual physical examination (only in case of video calls).
- ▶ Therapy modifications.
- ▶ Scheduling of in person visit if needed.

The software originally selected for video communication was Microsoft Teams; because of its widespread use in Italy, WhatsApp was used for the patients who could not use Microsoft Teams due to technical limitations or lack of help when needed.

Assessments

For patients who received two consultations or more, baseline demographic and clinical data were collected; for each single consultation the treating physician also registered: type (video/phone) and reason of the call, request by, assessments and intervention performed.

Patient/caregiver experience with TM consultations Interview

Four to 6 weeks after the first TM consultation patients who had at least two TM contacts were interviewed in order to evaluate their experience with the consultation. The questions asked during the interview were developed based on the available literature (4, 5) and covered the following main domains: communication,

impact on patient's health management, patient experience, technical issues and overall satisfaction. Overall satisfaction was assessed with the following question: 'Overall, how satisfied are you from the medical assistance received through the video/phone consultations of palliative care?'. Responses were gathered using 1–5 Likert verbal scales; in order to prevent mechanical responding and halo error, some items asked about frequency (from 1—'never' to 5—'always'), others about intensity (from 1—'not at all' to 5—'extremely') and others about agreement with a statement (from 1—'definitely no' to 5 'definitely yes'); some items asked about advantages but most of them regarded potential problems/disadvantages in order to limit acquiescence. Open comments were also gathered when appropriate, and a final open-ended question about positive and/or negative aspects of TM consultations as compared with in-person visits concluded the interview.

Whenever possible, interviews were performed with the patients, or, in alternative, with the caregiver who had actively participated in the consultations. Questions asked were similar to those included in the patients' interview but focused on the caregivers' perception of the patient TM experience, with the exception of questions on attitude and overall satisfaction, which were aimed at assessing the perception of caregivers themselves.

Interviews were administered on the phone by clinicians different from those carrying out the TM consultations, and who had an extensive experience in dealing with advanced cancer patients. Interviewers underwent a brief training on interview administration and met twice during the assessment period to discuss about issues related to the interview administration.

Statistical analysis

When planning the study, it was calculated that 65 responders would allow for the estimation of a two-sided 95% CI for the mean of the satisfaction score (main outcome) with a precision (half CI width) of 0.24 times its SD. Patient characteristics, user experience with TM consultation and feasibility outcomes were summarised using descriptive statistics (percentages and means for categorical and continuous variables, respectively) along with 95% CIs. Technology unavailability, lack of needed assistance and video consultation refusal were described by age groups, and age was treated as a categorical variable. χ^2 test was used to examine the association between categorical variables. A pairwise deletion (available case analysis) was performed, and only cases with all required variables were included in the analysis. Data analysis was performed with STATA V.16 software (Stata).

RESULTS

From May to December 2020, 572 consecutive patients attending the outpatient PC unit were screened for

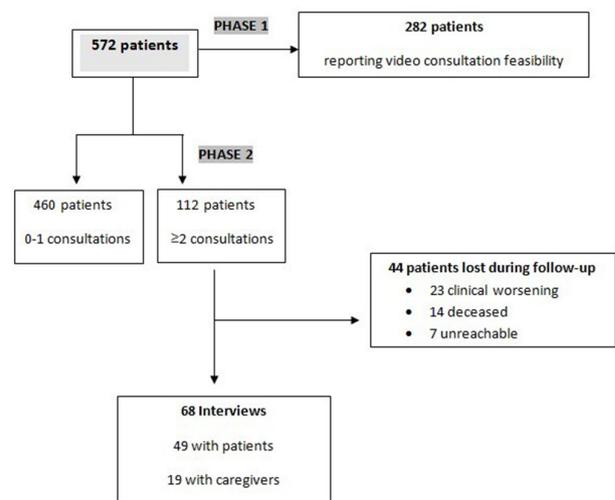


Figure 1 Screening and eligibility flow chart.

feasibility of the video consultation (figure 1). Of the 572 screened patients, 112 were contacted at least twice by a PC physician for remote consultation and were therefore eligible for the data collection on the service description and for the patient/caregiver experience interview. Of these, 68 were interviewed (49 patients and 19 caregivers) whereas 23 patients had a clinical worsening preventing the interview, 14 died and 7 were unreachable.

Video consultation feasibility screening

Among the 572 screened patients, 78%, 39% and 23%, respectively, declared to own a smartphone, a computer with a webcam or a tablet; 58% had an email address and 61.5% had availability of a full internet connection. The availability of at least one connection device (ie, smartphone, tablet or computer with a webcam) together with and unlimited internet connection and email address was 52%, indicating that 276 patients (48%, 95% CI 44% to 52%) did not have the needed technology. A total of 233 patients (41%) expressed the need of additional help for attending videocalls but 98 of them (17% out of the 572 screened, 95% CI 14% to 20%) did not have someone who could help. Acceptance of potential video consultation independently from technology and help need, was expressed by 78% patients (95% CI 75% to 81%). Overall, for 282 patients (49% of those screened, 95% CI 45% to 52%) a video consultation was potentially feasible as they had technology availability, did not need help (or had help if needed) and reported to accept it.

Figure 2 reports technology unavailability, lack of needed assistance and video consultation refusal by age groups. As expected, older age was associated with higher technology unavailability ($p=0.000$), with lack of needed assistance ($p=0.000$) and videocalls refusal ($p=0.000$).

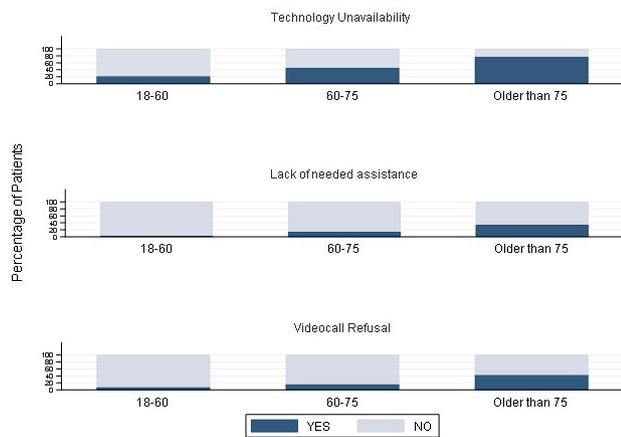


Figure 2 Technology unavailability, lack of needed assistance and video consultation refusal by age groups.

Service implementation description

The characteristics of the 112 patients contacted at least twice via video or phone consultations, are listed in [table 1](#). The mean follow-up TM consultations period was 29.9 days with an average of 2.9 calls per patient. Twelve patients (10.7%) had at least one video call.

In total 353 TM consultations were carried out with the 112 patients ([table 2](#)), 308 (87%) were phone consultations and the remaining were video consultations. In most cases (63%), the TM consultation was requested by the patient or their caregiver and the reasons included mainly uncontrolled symptoms (66%), new symptoms onset (20%), clarifications about therapies (37%) and update on examinations and diagnostic tests (28%). Fifty-six per cent of the calls were done with patients, 30% with caregivers and 14% with

Table 1 Characteristics of the contacted patients (N=112)

Characteristics	N (%)
Age, mean (SD)	65 (1.4)
Sex	
Female	59 (52.7)
Male	53 (47.3)
Primary cancer	
Lung	24 (21.4)
Breast	19 (16.9)
Prostate	9 (8.1)
Skin	9 (8.1)
Gastrointestinal	9 (8.1)
Pancreas	9 (8.1)
Urinary system	7 (6.2)
Gynaecologic	6 (5.3)
Sarcoma	6 (5.3)
Thyroid	4 (3.5)
Head and neck	2 (1.8)
Haematologic	2 (1.8)
Other	6 (5.3)

Table 2 Characteristics of consultations (N=353)

Characteristics	N (%)
Type of consultation	
Video	45 (12.8)
Phone	308 (87.2)
Requested by	
Physician/nurse	127 (36.9)
Patient/caregiver	217 (63.1)
Reason*	
Reschedule appointment	81 (22.9)
Uncontrolled symptoms	232 (65.7)
New symptoms onset	71 (20.1)
Adverse effects from therapies	68 (19.3)
Update on examinations/diagnostic tests	100 (28.3)
Clarifications about therapies	132 (37.4)
Drugs prescription	37 (10.5)
Activation of home care services (?)	25 (7.1)
Facilitation of communication with other specialists	55 (15.6)
Other	85 (24.1)
Type of evaluation performed during the call*	
COVID-19 symptoms	107 (30.3)
Cancer symptoms' intensity	240 (68)
Other	24 (6.8)
Type of Intervention performed during the call*	
Appointment rescheduling	153 (51.5)
Therapy modifications	172 (70.2)
Activation of home care services	40 (11.3)
Hospice activation	4 (1.1)
Emergency Room or hospital referral	4 (1.1)
Participants during the consultation	
Patient	197 (55.8)
Caregiver	107 (30.3)
Both	49 (13.9)

*More than one answer was allowed.

both. The interventions most commonly carried out as a result of the TM consultations were therapy modifications (70%) and appointment rescheduling (51%).

User experience of care with TM consultations

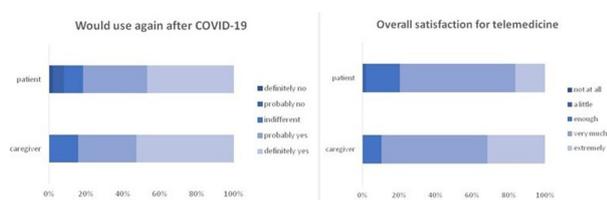
In total, 68 interviews were carried out, 49 with patients and 19 with caregivers. Patients and caregivers evaluated the TM experience very positively with an overall 1–5 satisfaction score of 4.1 (95% CI 3.9 to 4.2, N=68) on the final item 'Overall, how satisfied are you from the medical assistance received through the video/phone consultations of palliative care?' (data not reported in table). For each item of the interview, [table 3](#) shows average scores and percentage of patients reporting the most positive response ('never' and 'not at all' for negatively worded items and 'always' or 'extremely' for positive ones) by type of responder. Overall, both patients and caregivers evaluated the TM experience very positively, with the vast majority of them (79% or more) expressing no difficulty in communication with the doctor or in obtaining the

Table 3 Patient and caregiver experience with phone/video consultations (N=68)

With reference to the phone/video calls you had with the PC physician in the last period:	Patient (N=49)		Caregiver (N=19)	
	Mean (SD)	%*	Mean (SD)	%*
Did you happen not to be able to explain (your /your relative) symptoms to the doctor? ^(a)	1.2 (0.4)	82	1.2 (0.4)	79
Did you happen to have difficulties in understanding dosages or how to take the prescribed drugs? ^(a)	1.1 (0.3)	92	1.2 (0.4)	84
Did you happen to lack time enough to talk with the doctor? ^(a)	1.1 (0.3)	90	1.2 (0.5)	79
After the phone/video calls, how hard was it to obtain the recipes of prescribed drugs? ^(b)	1.3 (0.7)	85	1.3 (0.7)	85
Have (you/your relative) felt neglected as compared with when (you/he/she) would come regularly at the hospital? ^(b)	1.1 (0.5)	92	1.3 (0.8)	84
Did you happen to feel uncomfortable, during the phone/video calls? ^(b)	1.0 (0.1)	98	1.1 (0.3)	89
Has it been relevant for (you /your relative) to reduce the number of times you came to the hospital? ^(c)	3.3 (1.1)	14	3.5 (1.4)	36
Have (you /your relative) felt safer not to come frequently to the hospital? ^(c)	2.9 (1.2)	6	3.1 (1.4)	21

(a) Negatively phrased item with responses ranging from 1='never' to 5 'always'.
(b) Negatively phrased item with responses ranging from 1='not at all' to 5 'extremely'.
(c) Positively phrased items with responses ranging from 1='not at all' to 5 'extremely'.
*Percentage of patients reporting an 'extremely positive score'.
PC, palliative care.

prescribed drugs (table 3, items 1–4); also, the total lack of feelings of neglect and discomfort during phone or video consultations was largely common (84% of responders or more). Reducing the number of accesses to the hospital was perceived somehow less important both for patients (average score of 3.3, with only 14% reporting this to be 'extremely' relevant) and for caregivers (6% reporting this to be 'extremely' relevant); consistently, patient feeling of safety was also limited (6% of patients and 21% of caregivers reporting the patient felt 'extremely' safer). Responders who had video consultations did not report any technical difficulty. Patient and caregiver general attitude for and satisfaction with TM are described in figure 3. More than 80% of patients and of caregivers responded positively to using the TM service after the end of COVID-19 pandemic and, consistently, their overall satisfaction was high, with average patient satisfaction score of 3.9 (95% CI 3.7 to 4.2) and average caregiver satisfaction score of 4.2 (95% CI 3.9 to 4.5). Positive aspects reported by the responders in the final open-ended question of the interview included travel limiting and time saving. However, the downside reported by most responders were the impossibility to undergo a physical examination, if needed, and lack of interpersonal relationship with the physicians.

**Figure 3** Patients' and caregivers' attitude for and satisfaction with TM. TM, telemedicine.

DISCUSSION

Providing remote medical consultations to patients in need of PC, especially those in underserved areas or in need of reducing number of accesses to the hospital, has become easier thanks to the newly available communication technologies. However, during the years, several barriers have been encountered limiting the extensive use of TM. Limitations are mainly related to unavailability of the technology needed, patients' low IT literacy, especially for the elderly, and the lack of in-person communication.²² The current COVID-19 pandemic situation has though made the use of TM a very useful option.

In this paper, we describe the feasibility of TM consultations in a PC outpatient population by also providing a thorough description of the implementation and of the user experience of care. Around half of the screened patients were potentially eligible for a video consultation (accepted it, had technology available, were able alone or had help to use it). Among those who had had at least two TM contacts, we found a high overall satisfaction of both patients and caregivers (average overall satisfaction score of 4.1 on a 1–5 scale) with over 80% of interviewed patients and caregivers answering positively to the alternative of using this service also after the COVID-19 pandemics.

Overall, the acceptance of potential video consultation, independently from technology and help need, was expressed by 78% patients (95% CI 75% to 81%). No relevant issues regarding communication during the consultations were raised and no technical issues were met during video-calls. Still, video calls actually performed during the 8 months follow-up were only a minority of the overall TM consultations volume (45 calls over a total of 353, related to less than 11% of the enrolled patients). These data are in agreement with

the limited feasibility of video consultations emerged in the screening phase and also with the data reported in literature.¹⁷ Limited experience in using communication technology was found also in another study,²³ reporting on implementation of TM in resource-limited setting. Similarly to previous studies^{24 25} and as expected, we found that elderly patients have a higher need of assistance for participating in the video consultations and in general lower acceptance of the service.

In agreement with previous studies in PC and other settings²⁶⁻³¹ and user satisfaction with TM was high. However, reducing the number of accesses to the hospital and feeling of safety was perceived somehow less important. It is interesting to note that a study carried out in cancer patients seen in radiation oncology clinics,³² showed high average scores across all measured domains of patient satisfaction, but found no significant differences between TM and in-person visit respondents. Small satisfaction differences were similarly shown between video and in-person visits in a retrospective study comparing also pre-COVID-19 and during COVID-19 study periods.³³ This may be due to the skewness of satisfaction scores which imply low sensitivity of the scales but also to the fact that patient care experience is associated to other factors (ie, trust in physician, time dedicated during the visit, other patient related characteristics like sex and age). This suggest that further research into visit-related factors and the patient-provider connection over TM is needed to plan effective TM interventions.

This is a single-centre study carried out in a comprehensive cancer centre in of one of the biggest cities in Italy and this may have reduced results generalisability. In addition, a 39% non-response rate to the user experience interview is a study limitation potentially inducing bias; however, such non-response rates are somehow expected in PC setting and this is the reason we choose to interview caregivers who participated in the TM intervention when patients were not available. One further potential limitation is selection bias, that is, those participating in the study were more likely to be satisfied with the service since they might already be more familiar with the technology needed. However, considering the special conditions imposed by the pandemic, it can be assumed that some of the participants would not have opted for the service under normal circumstances. This implies somehow a wider representativeness of the study sample, limiting the selection bias. Finally response bias may have induced patients and caregivers to increase the degree of their satisfaction in order to seek for approval by the treating clinician; to limit this effect, interviews were performed by personnel other than physicians and nurses normally caring for patients.

Despite a high potential acceptability of video consultations and the considerable satisfaction for TM above mentioned, more data are needed about clinical efficacy of this model of delivering PC. In

fact recent clinical trials failed to prove efficacy of similar interventions³⁴ and potential negative effects on clinical outcomes should be carefully excluded before TM is considered a substitute of in person visit. Previous evidences have shown potential human resources saving and, in general, costs reduction following systematic TM implementation¹¹; however, this is not necessarily true as it depends on whether TM is used in parallel with, or as a replacement for, traditional visits.¹¹ TM could be implemented as an addition to the inperson clinical care pathway contributing to improve continuity of care and identifying timely emerging problems that need prompt in person assessment and interventions. Implementation trials designs on specific models of palliative TM are therefore certainly needed to evaluate cost-effectiveness.

Continuity of care, communication and sharing of care strategies with patients, caregivers, PC and other professionals involved, both in cancer centres and at the community level, is crucial to improve clinical outcomes. TM and information technology will be playing a role in this task and for this reasons more resources, innovation and robust research are essential to establish an empirical evidence.

Contributors CB, AC and EZ were involved in the conception and study design. EZ, MS, CP, PB, SLD, MC and SZ were involved in the data collection process. EZ designed data collection tools. CB, MS, CP and EZ cleaned and analysed the data. CB and MS prepared the original draft. All authors contributed to reviewing and editing the final draft. CB is the guarantor of the content.

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Competing interests AC has received honoraria from Angelini, Italfarmaco, Shionogi, Kyowa Kirin, Molteni, Pfizer/ Eli Lilly Italia Spa, Mundipharma and Ipsen Spa institutional grant.

Patient consent for publication Consent obtained from parent(s)/guardian(s)

Ethics approval The study was approved by the institutional review board (INT 76/20). Oral informed consent to study participation was obtained before each TM consultation and before the final phone interview.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request.

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